

How do we get our Daughter back? Parents' Perspectives on Recovery from Anorexia Nervosa

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Abstract

Background: Anorexia Nervosa is a severe mental illness most commonly occurring during adolescence. As a parent, caring for a child with Anorexia Nervosa can quickly consume all aspects of family life, leading to frustration, feelings of burden and increased levels of anxiety and depression. Despite the impact of the illness on parents, there is a surprising lack of literature drawing on parents perspectives of recovery, particularly during adolescence.

Objective: To gather the lived experience of parents caring for an adolescent daughter throughout recovery from Anorexia Nervosa.

Method: Eight participants, seven mothers and one father, were recruited from two specialist outpatient eating disorder services. All parents had an adolescent daughter between the ages of fourteen and eighteen in recovery from Anorexia Nervosa. The study used a qualitative design and the research lead completed semi structured interviews with each of the eight parents. The interviews were transcribed and analysed using Interpretative Phenomenological Analysis.

Results: Analysis of the data revealed one overarching super-ordinate theme, 'a journey to recovery' encompassing a further four super-ordinate themes. The four super-ordinate themes included "a secret exposed," "anorexia is tearing our family apart," "how do we get our daughter back?" and "accessing help." The results of the analysis are discussed in line with relevant theory and ideas for clinical practice are highlighted.

Conclusion: The current study highlighted the invasion of Anorexia Nervosa and its ability to tear the family apart. The study emphasises the adolescents need for emotional support throughout recovery but highlights the difficulties for parents due to the adolescents stage of development, their strive for independence and reluctance to accept their difficulties.

Keywords: Anorexia Nervosa (AN); Anxiety; Depression

Introduction

Anorexia Nervosa (AN) is a significant mental illness with one of the highest mortality rates [1]. Within the Diagnostic and Statistical Manual (DSM-5), AN is characterised by a persistent restriction of energy intake, leading to a body weight significantly lower than expected for age and sex, taking into account an individual's developmental trajectory and physical health. Despite significantly low body weight, individuals with AN experience a distorted body image, a strong fear of gaining weight and typically lack insight into their difficulties. Although other forms of eating disorder exist, due to the varied presentations within each eating disorder and the potential this has to impact upon recovery, this research will focus purely on AN.

AN most commonly occurs during adolescence, with research suggesting that late adolescence, between the ages of fifteen and nineteen years, accounts for approximately 40% of all cases [2-4]. In adolescence it is important to consider the added complexities due to

this being a developmentally sensitive time in which poor nutrition, hormonal changes and high levels of stress disrupt brain maturation [5].

Treatment for young people with AN differs to adults due to the inclusion of parents in treatment recommended by NICE guidelines [6] for all cases. In adolescence, the impact of the illness on parents could potentially be more intrusive due to the young person living at home with parents who are often responsible for implementing meal programmes at home. Treasure, Schmidt and Macdonald [7] have identified three domains which could potentially be problematic in caring for a loved one with an eating disorder.

Firstly, the life threatening nature of AN can cause anxiety and frustration due to the urgent need to eat and associated behavioural difficulties [8]. Secondly, without the correct education and understanding of AN, parents can unintentionally place responsibility on the individual and believe they are choosing to act in this way. AN can impact on relationships within the family and higher expressed emotion often results in parents and carers reacting to AN with

emotions such as guilt, anger and shame [9,10], resulting in less effective communication [7]. Thirdly, the eating disorder can invade family life and can quickly become the central focus of the family [8,10]. In line with this, families living with a young person with an eating disorder have rated their family functioning significantly lower than control groups [11] and parents often describe an associated impact on their own mental and physical health [12-14].

Mental health difficulties in childhood can leave parents with a sense of powerlessness and uncertainty as to how to support their child; taking away a vital part of a parent's role [15-17]. When specifically discussing the need to access support for a child's eating difficulties, parents have highlighted distress that they had not recognised their child's eating difficulties sooner and report feeling helpless when previous beliefs that they would be able to fix the problem themselves prove to be untrue [17]. Mental health services are available to support parents in managing their child's mental health difficulties and therefore it is essential that research continues to investigate parent's perceptions of this treatment and gather information to allow parents to manage their own emotional distress and support their child to recovery.

Variation exists among parents, young people and clinicians as to what is considered to represent recovery from an eating disorder [18,19] highlighting the need to gain information on the lived experience of recovery rather than rely on professional decisions or basing judgments on diagnostic criteria alone. A surprising lack of literature has investigated parents' perceptions of recovery during adolescence. In addition, previous studies have failed to provide a clear definition of recovery, resulting in varied presentations, including some daughter's still undergoing inpatient treatment, therefore questioning whether recovery had been reached at all.

This study aims to address some of these limitations using a qualitative methodology to gather parents' experiences of their daughter's recovery. Focusing on parents of adolescents who are in recovery from AN at the time of the study will allow parents to reflect on the whole recovery process and capture parents' experience whilst their daughter is in recovery. Recovery will be assessed by clinicians using the definition by Bardone-Cone et al. [20], capturing both the psychological aspect of recovery in addition to weight gain and providing some standardisation to recruitment.

Method

Study setting

The study was completed within two specialist community child and adolescent eating disorder services within the North of England. These are multidisciplinary teams, comprised of consultant psychiatrists, psychologists, dietitians and nursing staff. The teams offer intensive support to children and their families to support recovery from an eating disorder.

Participants

Purposive homogenous sampling was used to select participants on the basis that they can provide insight into a specific phenomenon rather than that they are representative of the general population [21]. The overall sample included 8 participants from two specialist eating

disorder services. The sample included seven mothers and one father. All parents were living at home with their spouse who was invited to take part, however only one father accepted this invitation. A parent was eligible to take part in the study if they had a daughter between the ages of fourteen and eighteen who was assessed by their clinician as meeting the recovery criteria.

Ethical approval was gained to conduct this study and participants were given an information sheet outlining details of the study prior to providing written consent to participate. Semi structured interviews were completed individually with each parent and were subsequently transcribed for analysis.

Data analysis

Data were analysed using Interpretative Phenomenological Analysis (IPA); a research method particularly focused on exploring the lived experience of an individual. Analysis worked through the steps outlined in ref. [21] and the researcher kept a reflective diary and had regular supervision to examine her own preconceptions of AN and reflect on how this may have influenced the research at different stages. A series of measures for ensuring quality and validity of qualitative research have been outlined by Yardley [22] and these were followed during the analysis.

Results

Interviews lasted between forty two minutes and one hour twenty minutes with an average duration of 59 min. Extracts from participants' transcripts have been included throughout the results section to provide supporting evidence and ensure sensitivity to the context of the interview. In this way, the participants own words are retained throughout the results. Pseudo names have been provided in order to maintain confidentiality. Five overarching themes emerged, each of which contained at least two subordinate themes pictured in Table 1. Each of the super-ordinate themes were present in all eight of the transcripts, suggesting that the themes are a valid representation of all participants' experiences.

A journey to recovery

One overarching super-ordinate theme, a *journey to recovery*, emerged as both a theme within the data and a theme within each of the remaining four super-ordinate themes. All participants described their experience as a journey from recognition of AN to recovery. Parents described different stages within recovery with a sense of the journey being changeable. A number of parents also highlighted the difference between physical and psychological recovery and commented that at times, one may need to take priority over the other, "I was more concerned about her physical health at that point," (June).

Within the subtheme, lasting impact, all participants commented on the ongoing impact of the illness and described being on the lookout for signs that the 'monster' is returning. Several parents commented on a fear that the journey was not over, "I don't feel like this is all completely over and done with and we are marching off into the sunset," (Lisa). "It will never go away; it's never going to go away" (Sue). Several parents hoped for further improvements and others described stronger relationships as a consequence of their shared experience.

Journey: Stages of recovery, lasting impact			
A secret exposed	Anorexia is tearing our family apart!	How do we get our daughter back?	Accessing help
In the dark: not knowing and not wanting to know	Losing your daughter	Learning to do something different	Frustration
Searching for a reason	Three's a crowd	Determination	Excellent support from specialist services
Lost	Marital conflict	Supporting your daughter and staying one step ahead of anorexia	Extended support
	Family life destroyed	Guided by the young person	Dealing with other people's perceptions
	Distress		

Table 1: Results showing the stages of recovery.

A secret exposed

All eight parents commented on a journey of recognition; exposing the secret that is controlling their daughter. In the subtheme, *in the dark: not knowing and not wanting to know*, parents described noticing small changes and attributed these to normal teenage development. Vicki and Ann described suspicions that these problems were more severe yet they were reluctant to accept this, potentially due a fear of the journey that would lie ahead. "It was always in the back of my mind that it wasn't the diabetes, the reason she was losing weight and I suppose for a while, that's what I believed was the reason," (Vicki). Parents described their daughter as "hiding" the illness and "playing the game", reflecting a realisation that they were being deceived.

Within the subtheme, searching for a reason, parents described seeking understanding of how they had got "to this place" (Sue). Parents speculated as to what might have caused the difficulties, and often blamed themselves or felt blamed by others. Vicki's comment reflects her attempts at trying to understand this illness from the perspective of her daughter "I was trying to understand what she was going through". Within the subtheme lost, parents described feeling like they were on the "back foot" (Lisa), not knowing "where to turn" (Lucy). The uncertainty is captured in a quote by Vicki "we didn't know what was right and what was wrong," and a sense of urgency is depicted in Alice's quote "we have to survive somehow."

Anorexia is tearing our family apart

Within this super-ordinate theme, parents described the destruction caused by AN and its impact on the whole family. Within the subtheme losing your daughter, parents described a loss due to the control of AN and also to professionals, commenting on the difficulties accepting support due to a belief that this is their role as a parent. "It made me feel like a bit of a failure" (Vicki), "I can do it on my own" (Lucy). Within the subtheme three's a crowd, parents desperately pleaded with their daughter in an attempt to push past AN. Lucy describes trying to get her daughter to recognise the extent of her illness, "Why aren't you eating, you need to eat more, do you realise how much weight you're losing." Similarly Sue describes an ongoing battle, "here we go again it will be fighting for dinner. And that was it, the days, months went by like that, fighting."

In the subtheme *marital conflict*, parents described difficulties in the marital relationship either due to differences in understanding or

disagreements as to the best way of managing the illness. This is summarised by Alice, "...really we thought that our marriage would not survive." A subtheme of *family life destroyed* depicts a feeling of helplessness as AN invades the family and parents described a feeling of putting their life on hold or being "robbed of our life (Sue)." A subtheme of distress depicts the impact of the illness on parental mental and physical health with increases in anxiety and low mood and some parents accessing their own psychological support or medication.

How do we get our daughter back?

All parents identified a subtheme of *learning to do something different* in order to support their daughter throughout recovery. Parents described a period of learning from which they were better equipped to support their daughter. Sue's comment reflects a period of not knowing with a belief that existing skills and her unique knowledge of her daughter would allow her to fix the problem. "You are so naive in the beginning thinking that because were her mum and dad we will fix it, we'll get her better, she'll be alright, you know, and it just didn't turn out like that at all." Parents also identified a subtheme of *supporting your daughter and staying one step ahead of anorexia*, in which they describe providing an intense level of support throughout recovery. The following quote from Lisa demonstrates how exhausting it is monitoring her daughter's behaviour to this extent, "you go to bed at night exhausted or you don't sleep or you're awake at two checking on them." Parent's experiences also revealed a subtheme of *determination* in which parents reported doing whatever it takes to ensure their daughter's survival. Within the subtheme *guided by the young person*, parents began to recognise their daughter's stage in recovery and allowed her some control through setting the pace of recovery.

Accessing help

All parents described accessing support to help them through their journey to recovery. Parents described frustration with access to support for their daughter and worries about the impact of this on further weight loss. Within this subtheme of *frustration*, parents described determination to get appointments for their daughter, "I am going to ring CAMHS every day until they offer an appointment" (June). In the subtheme *excellent support from specialist services*, parents commented that once they had accessed support it was to a high standard, particularly commenting on availability and

reassurance. In the subtheme *extended support*, parents commented on family, friends and work helping to manage the demands of the illness. In the subtheme *dealing with other people's perceptions*, parents highlighted the impact of other people's misperceptions around anorexia and the detriment this could cause to recovery. Lucy reflected on the anger and frustration this caused her as a parent, "In my mind I am so angry I want to punch them in the face, because I think you don't know anything about it."

Discussion

The super-ordinate theme '*Anorexia is tearing our family apart*' represents the devastation caused by AN, not just for the adolescent but for the whole family. Looking back at the literature review, the impact of the illness on family life is a theme emerging in previous studies of parents' perceptions of recovery [23,24] and in the literature on parents' experiences of caring for a daughter with AN [10,25]. The invasion of AN into family life dominated parents' descriptions of their experience and highlights that this is a mental illness experienced by the whole family, not just the sufferer. This is in line with NICE guidelines [6] that parents should be involved in the treatment of AN in adolescence and the evidence base for family therapy as an effective treatment [26], in particular, the Maudsley family-based treatment [27].

In the subtheme, '*losing your daughter*', parents comment on the loss experienced throughout the illness. Parents felt they were losing their daughter to AN, a theme which is also represented in earlier research by Cottee-Lane et al. [25] in which parents depict a "dreadful monster" which has taken over their child. Parents described feeling lost alongside their child with previous ways of responding to their child's behaviour no longer proving effective. In the current study, parents also reported a sense of loss to professionals; feeling their role in caring for their daughter was taken away from them when they accepted support. Parents' comments reflect feelings of failure and distress in relation to this loss. Looking back at the literature review, this theme of loss is briefly mentioned in the study by Sharkey-Ogner [28] in which parents describe the need to step back and allow their daughter to take responsibility for her own recovery, but do not reflect on the emotional impact of this. Similarly, in the study by Cohn [29] parents commented on the need to rein in their tendency to lead their daughter's recovery but similarly, do not describe any associated emotions. One reason for this could be the participant's age with adolescents transitioning to adulthood in the study by Sharkey-Ogner [28]. However, the study by Cohn [29] does not specify the daughter's age. Another possible explanation could be the number of years since recovery and as a consequence, the emotional impact of this experience could be forgotten.

Many studies have identified parent's experiences of accepting help for their child's mental illness [15,17,30,31]. Buus et al. [15] carried out a qualitative study on the experience of parents whose child attempted suicide. Similar to feelings of helplessness identified in the current study, parents described a feeling of powerlessness in relation to the mental illness and reported feelings of shame that they were unable to prevent their child's behaviour. A study by Thomson et al. [17] looks specifically at parents' perceptions of accepting support from CAMHS for an eating disorder. Similar to the findings of the current study, parents commented on an ambiguity in accepting support for their child, believing that they should have been able to 'make' their child better themselves. These comments demonstrate the ability of a mental illness to challenge a parent's role and their innate desire to look after

their child. Specifically with eating difficulties, being unable to feed their child and see them become incredibly poorly through a lack of food, touches the parents in a deep and profound manner. In line with attachment theory, feeding a baby is more than just taking in milk and nutrients; it is the beginning of an attachment relationship [32]. The dependency on food for survival can result in powerful emotions around feeding and can link to a mother's perception of her ability to care for her baby [32]. Eating difficulties in adolescence can potentially cause some of these powerful emotions to re-surface.

Recognising these feelings of helplessness, the Maudsley family-based treatment for AN addresses these feelings in the first stage of their treatment [33]. Within this model, professionals make a conscious effort to acknowledge the shared responsibility of recovery, recognising their expertise in the area but emphasising parents' knowledge of their family and their role in facilitating recovery.

Within the current study, parents highlighted the impact of other people's misperceptions of AN and the detrimental impact this could have on recovery. Parents reflected on a lack of public awareness and highlighted the negative impact of the illness' portrayal in the media. Similar concerns have been highlighted in previous studies investigating the experience of caring for a daughter with an eating disorder. Parents have reported a lack of understanding around the illness from family and friends, feeling that others could not appreciate the true extent of the difficulties the family were facing [25,34]. In addition, in a study by McCormack and McCann [10], parents talk explicitly about stigma and the detrimental impact this had on themselves and their daughter. Parents felt they were acting in the young person's best interest by concealing the illness due to beliefs that it may be poorly understood or not accepted. O'Hara and Smith [35] investigated the portrayal of eating disorders in the media looking at articles printed in seven US newspapers over one year. Over this period, two hundred and ten articles included content about eating disorders but only a minority reflected on the severe physical impact and complicated treatment, potentially minimising the impact of the illness. Of the ninety articles which discussed aetiology, the factor discussed most frequently was parental influence which would understandably have a detrimental impact on parents' willingness to seek treatment [36]. This blame based stigma has been found to significantly contribute to carers' levels of distress [34]. Feeling stigmatised and blamed can have a negative impact on parents' willingness to seek treatment therefore, delaying access to appropriate support. Access to quicker evidence based support can improve recovery rates, reduce relapse and prevent admission to inpatient services [37], therefore reducing stigma and promoting early intervention should be seen as a priority in working towards quicker recovery from an eating disorder.

Within the subtheme, '*frustration*', parents described difficulties accessing support for their daughter. Parents expressed frustration at waiting times for specialist services and reported the detrimental impact of further weight loss. Similarly, parents in previous studies have reported frustrations that their GP had not initially recognised the presenting difficulties as an eating disorder [10,25]. NHS England have recently published access and waiting time standards for children and young people with an eating disorder [38]. This guideline outlines the role of increased funding to transform services in England for the treatment of children and young people with an eating disorder. The standards state that all referrals will be seen within four weeks and one week for urgent cases; addressing some of the difficulties experienced by parents in the current study. Recognising that an eating disorder has

a wider impact on the family, all services will be required to meet the broader needs of the family as well as the young person [39-46].

Limitations of the current study

Participants varied in terms of their adolescent's duration of illness and also the treatment received, with one of the seven adolescents being admitted to an inpatient hospital as part of their treatment. This has created variation in the sample which could have affected the results. However, these limitations have resulted in a diverse sample with common themes across participants' experiences, suggesting that the themes are a shared experience of parents supporting their daughter to recovery from AN, rather than an experience which is limited to one shared characteristic such as the duration of the illness.

Ideas for future research

The current study only looked at parents' perspectives of recovery in adolescent females with AN. It will be interesting for future research to investigate the experience of caring for a son with an eating disorder and also to investigate recovery in other eating disorders.

The implementation of access and waiting time standards for children and young people with an eating disorder [37] will result in a transformation to current eating disorder services. It will be important for future research to assess both adolescent and parent perspectives of these transformations to ensure the service is meeting their needs. It will also be important to investigate the longer term impact of these transformations on recovery.

Conclusions

The current study highlights the invasion of Anorexia Nervosa and its ability to tear the family apart. Focusing on the experience of parents has highlighted the need for services to provide carers assessments and offer support for parents throughout the recovery in addition to supporting the adolescent themselves. The findings emphasise the impact on family life, highlighting the crucial role of family therapy in an adolescent's recovery.

New developments in eating disorder services as a result of access and waiting time standards will hopefully lead to quicker recognition of the illness and earlier access to services. Future research in this area will be helpful to consider the impact of these changes on the experience of both parents and young people.

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